

Overview

Points To Remember About Paget's Disease

- Paget's disease causes bones to grow too large and weaken.
- The disease is more common in older people and those of northern European heritage. Men are more likely than women to have the disease.
- Signs and symptoms can include pain, enlarged and broken bones, and damaged cartilage in joints.
- Doctors are not sure what causes Paget's disease. They think that a virus may cause it in some cases. It also tends to run in families.
- Doctors usually diagnose Paget's disease with x-rays.
- Paget's disease is treated with medicines, diet, exercise, and surgery. Following a doctor's treatment plan may lower the chance of major changes in your bones.

Paget's disease of bone is a long-lasting or chronic disorder that causes bones to grow larger and weaker than normal. The excessive breakdown and formation of bone tissue causes affected bone to weaken leading to:

- Bone pain.
- Misshapen bones.
- Fractures or broken bones.
- Arthritis in the joints near the affected bones.

Unlike osteoporosis, which affects all bones in the body, Paget's disease usually affects just one or a few bones. The bones most commonly affected by Paget's disease include:

- Pelvis.
- Skull.
- Spine.

· Legs.

Complications

Paget's disease can lead to other medical problems or complications, such as:

- Arthritis.
- · Hearing loss.
- · Heart disease.
- · Kidney stones.
- Curve on the spine.
- Brain or spinal cord problems.
- Loose teeth.

Rarely people with Paget's disease can develop:

- Bone cancer.
- Vision loss.

Who Gets

Risk factors for Paget's disease include:

- Age. Paget's disease is uncommon in people under age 40 and grows more common as you age.
- Anglo-Saxon descent. Paget's disease is more common in certain geographical areas including England, the United States, Australia, New Zealand, and Western Europe. It is not common in Scandinavia, China, Japan, or India.
- Family history. Paget's disease tends to occur in families.

Also, men are more likely than women to have the disease.

Symptoms

You may not know you have Paget's disease because many people with the disease do not have symptoms. Sometimes the symptoms are mistaken for arthritis or other disorders. In other cases, complications of the disease may cause the symptoms.

Symptoms can include:

- Pain, which may occur in any of the bones affected by the disease or result from arthritis, a complication that may develop.
- Headaches and hearing loss, which may occur when Paget's disease affects the skull.
- Tingling and numbness in arms and legs, due to pressure on nerves caused by enlarged

vertebrae.

- Bone changes, which usually happen in more advanced cases and may include:
 - Increase in head size.
 - Bow shape of a limb.
 - o Curvature of the spine.
- Hip pain, which may occur when Paget's disease affects the pelvis or thighbone.
- Damage to cartilage of joints, which may lead to arthritis.

Paget's disease can affect any bone or bones, but usually occurs in:

- Spine.
- Pelvis.
- Legs.
- Skull.

Generally, symptoms develop slowly and the disease does not spread to normal bones.

Causes

Doctors are not sure what causes the disease. Doctors think a virus may cause Paget's disease in some cases and are studying viruses to try to find ones that may cause the disease.

Paget's disease tends to occur in families. Research suggests that having a close relative with Paget's disease makes you more likely to develop the disorder than someone without an affected relative.

Diagnosis

Doctors use the following tests to diagnose Paget's disease a:

- X-ray.
- Blood test.
- Bone scan.
- Bone biopsy.

X-Ray

Paget's disease is almost always diagnosed using x-rays. Your doctor will order an x-ray to see if your bones are different from other bones and affected by Paget's disease.

Blood Test

Your doctor may order a blood test to check for the enzyme alkaline phosphatase. This test can indicate either Paget's disease or another condition such as liver disease. If you blood contains

high levels of the enzyme, it may be a sign of the disease.

Bone Scan

A bone scan is a test that helps doctor's identify which bones are affected by Paget's disease. You may have the test to help your doctor understand the extent of the disease.

During a bone scan, a safe amount radioactive substance is injected into a vein in your arm. The substance circulates through the bloodstream and "high-lights" places in your skeleton where Paget's disease may be present. collects in areas where there is increased blood flow and activity of bone-forming cells characteristic of Paget's disease.

Bone Biopsy

In rare cases, doctors remove a small sample of bone and examine it under a microscope. Your doctor may recommend a bone biopsy if x-rays do not confirm the presence or absence of the disease.

Treatment

Doctors treat Paget's disease with:

- Medicines.
- Diet.
- Exercise.
- Surgery.

The goal of your treatment is to:

- Slow down or stop bone breakdown and formation.
- Lower the risk of complications.
- Ease bone and joint pain.
- Repair fractures.
- · Correct bone deformity
- Replace joints damaged by the disease.

Prescription Medicines

The primary medicines your doctor may prescribe to treat the disease include:

- Bisphosphonates are a type of medicine that are used to treat a variety of bone diseases.
 This type of medicine works by controlling the excessive bone breakdown and formation that occurs in Paget's disease.
- Calcitonin is a hormone made by the thyroid gland and regulates blood levels of calcium and phosphate and promotes the formation of new bone. Although this medicine may not be as effective as bisphosphonates, calcitonin may be prescribed for certain people.

Diet

If you have Paget's disease, you do not need a special diet. However, it is important that you keep your bones strong. Every day you should take:

- 1,200 mg of calcium.
- At least 400 IU of vitamin D every day.

After age 70, you should take 600 IU of vitamin D each day. If you have had kidney stones, talk with your doctor about how much calcium and vitamin D to take.

Exercise

Exercise is important because it helps you:

- Build strong bones and maintain your skeletal health.
- · Prevents weight gain.
- Keeps joints mobile.

Before starting a new exercise plan, talk with your doctor to avoid stress on bones affected by Paget's disease.

Surgery

Although medications can often regulate bone growth and minimize complications, surgery may be necessary to correct problems such as:

- Fractures. Surgery may allow fractures or broken bones to heal in a better position.
- Arthritis. A hip or knee replacement may be necessary if changes in the bones cause severe disability.
- Bone deformity. Cutting and realigning bone affected by Paget's disease can reduce pain in a weight-bearing joint. During the procedure, a surgeon may perform a procedure called an osteotomy.

Who Treats

Paget's disease can affect many parts of the body. You may need to see more than one type of doctor, including:

- Endocrinologist, a doctor who specializes in hormonal and metabolic disorders.
- Rheumatologist, a doctor who specializes in joint and muscle disorders.
- Orthopaedic surgeon, a doctor who specializes in bone injuries and disease.
- Neurologist, a doctor who specializes in treating the nervous system, including the brain, nerves, and the spine.
- Otolaryngologist, a doctor who specializes in ear, nose, and throat disorders.

Living With

If you have Paget's disease, the outlook is usually good. When you follow your doctor's treatment plan, you may lower the chance of major changes in your bones. Treatment can help you manage your symptoms but does not cure the disease.

Healthier Bones

It is never too early or too late to take care of your bones. The following steps can help you improve your bone health lower the chance of complications from Paget's disease:

- Eat a well-balanced diet rich in calcium and vitamin D. Good sources of calcium include:
 - Low-fat dairy products.
 - o Foods and drinks with added calcium.
- Good sources of vitamin D include:
 - Egg yolks.
 - Saltwater fish.
 - Liver.
 - Milk with vitamin D.

Some people may need to take nutritional supplements in order to get enough calcium and vitamin D.

- Get plenty of physical activity. Like muscles, bones become stronger with exercise. The best exercises for healthy bones are strength-building and weight-bearing, such as:
 - Walking.
 - Climbing stairs.
 - Lifting weights.
 - Dancing.

Try to get 30 minutes of exercise each day.

- Live a healthy lifestyle. Don't smoke, and, if you choose to drink alcohol, don't drink too much.
- Maintain a healthy weight is particularly important if Paget's has led to arthritis of the weight-bearing joints, such as the hip or knee. Excess weight can mean more stress—and pain—for affected joints.
- Prevent falls by:
 - Checking your home for dangers like loose rugs and poor lighting.
 - Installing grab bars and hand rails.
 - Using nonskid mats in the bathroom and tub.
 - Seeing your doctor regularly to have your vision checked.
 - Increasing your balance and strength by exercising every day.
- Seek support. It is important to take care of your physical and mental health. Living with Paget's disease can be stressful. You may find it helpful to speak to:
 - Social workers.

- Counselors.
- Mental health professionals.
- Other people with the disease.

Your doctor can help you find counselors or a support group.

Related Resources

U.S. Food and Drug Administration

Toll free: 888-INFO-FDA (888-463-6332)

Website: https://www.fda.gov

<u>Drugs@FDA</u> at https://www.accessdata.fda.gov/scripts/cder/daf. Drugs@FDA is a searchable catalog of FDA-approved drug products.

Centers for Disease Control and Prevention, National Center for Health Statistics

Website: https://www.cdc.gov/nchs

NIH Osteoporosis and Related Bone Diseases ~ National Resource Center

Website: www.bones.nih.gov

American Academy of Orthopaedic Surgeons

Website: http://www.aaos.org

American College of Rheumatology Website: http://www.rheumatology.org

If you need more information about available resources in your language or other languages, please visit our webpages below or contact the NIAMS Information Clearinghouse at NIAMSInfo@mail.nih.gov.

- Asian Language Health Information
- Spanish Language Health Information

Join a Clinical Trial

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Related Information

Información para pacientes de la enfermedad ósea de Paget

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Paget's Disease of Bone, Easy-to-Read Fast Facts

Paget's Disease of Bone, Questions and Answers about

Paget's Disease of Bone, Facts a New Patient Needs to Know

Paget's Disease of Bone, Information for Patients

Paget's Disease of Bone and Osteoarthritis: Different Yet Related

Paget's Disease of Bone Diagnosis